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ABSTRACT

A new approach to rehabilitation of the disabled and disadvantaged is necessary, but the problem of how to involve consumers and how to organize groups for community action is a big one. Moreover, citizen participation cannot be a substitute for basic improvement in the quality of service. Service agencies need to be decentralized and staff members need sensitivity training to reduce the gap between staff and client. This paper provides insight into the organizatien, goals, legal status, and techniques used by consumer participation programs. Related documents are available as VT 011 818 in this issue, and ED 037 878 and ed 038 790. (BH)

Consumer Involvement in Rehabilitation

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Introduction

The annual meeting of the Maryland State Welfare Conference had just adjourned after a very successful banquet. A rather pretty, slender, young black woman came up to the podium. She spoke to the newly-elected President of the Conference: "Congratulations on your election. I would like to become active in the Conference. I am on welfare." That encounter and the self-assured, dignified tone of the request captures and highlights the swift change that has taken place in our country in just a few years. The conversation would have seemed bizarre a decade ago. The Conference, then, was an organization of those well-to-do who wanted to help the more unfortunate—not a partnership. The concept of citizen participation has deep roots that extend back to very old ideas, but it has re-emerged only in the past few years. A discussion of consumer involvement in rehabilitation must be seen as taking place within a context of furious growth and major upheavals within our society and the institutional service systems where this deep-rooted idea is beginning to flower.

Consumer involvement—not to speak of consumer control—is an idea that runs counter to the traditional view of "noblesse oblige" and the modern thrust of professionalism.

"Noblesse oblige" characterizes the stance of the affluent reaching down to help the impoverished and implies a role-set of strong and weak, healthy and sick, powerful and powerless. At one point in the development of our society, it represented a progressive view. After all, it did require some commitment to caring, as contrasted with indifference and denial of any responsibility, to engage in any sort of relationship with "the natives." From that historical perspective, "Lady Bountiful" was a *radical* individual in contrast with her peers who never ventured on the other side of the tracks—not even on Thanksgiving or Christmas

Day. Today, the concept is viewed as a reactionary and singularly inappropriate approach to the problems of poor or disabled persons in a democratic society. It is described as the antithesis of progressive citizen involvement.

Professionalism is another force that is antithetical to the spirit of citizen involvement, since the concept of professionalism implies expertise, control, and monopoly of decision making. Sociologists who have studied the development of professions emphasize the aspiration of occupational groups for professional status which is achieved normally by obtaining legal sanction for exclusive jurisdiction over an area of work and knowledge. It is therefore difficult for a professional group—and especially one still striving for that status—to concede to the possibility that an untrained individual can render worthwhile service or that a *recipient* of service can participate in decision making. In a complex society where a great deal of knowledge needs to be integrated to guide proper intervention, it seems appropriate for those who have the requisite training to make the decisions if they are to be valid—and for the clients, patients, poor people, and other laymen to submit to this expertise. Doctors, therapists, social workers, lawyers, counsellors "know best."

Here again, an historical perspective ought to make us somewhat tolerant of this point of view. Professionalism developed largely as a reaction to the worst kind of amateurism: lack of standards; destructive handling of individuals; exploitation of the sick, feeble, aged; high rate of failures; unscientific procedures, etc. Protection of the public required the removal of untrained personnel from decision-making and the licensing of groups of experts to be responsible and accountable for actions taken.

What, then, has taken place to cause a powerful reaction against the concepts of professionalism and compassionate assistance of the weak by the strong? The answer is not simple. It involves a whole host of factors. Some are ideological. Others are political, and still others are in the realm of new therapeutic knowledge.

Yet, in an unexplainable way, all these forces have converged on this moment in history to propel the concept of citizen participation and power into an ever-widening group of institutional systems at the local, state, and national levels. The catalytic moment may have been the declaration of war on poverty—the 1964

Economic Opportunity Act—which gave sanction to a strangely ill-defined concept: Maximum Feasible Participation of the Poor. But that pronouncement was only a minor final step that unleashed forces that had been building for long periods of time and were converging from sources far removed and isolated from each other.

Today, it is not only the welfare mother who wants a part of the action; it is the student in a university or high school; the tenant in a public housing project; the patient in an institution. Throughout the country, groups are being organized as if they were anti-bodies trying to offset an infection in a human organism. In a sense, this is exactly what the new citizen groups are attempting to do: To stop the increasing depersonalization and accompanying alienation that results from a mass society with highly bureaucratized institutions.

As with any new idea—the translation into programs is haphazard, often inconsistent, confusing, and, at times, troubling. The boundaries of citizen participation and of the new concepts of community control have to be tested. The political heat that has accompanied the development of new forms of citizen power needs to dissipate somewhat and the research on such attempts must be analyzed. Some have tried to exploit the awakened desire, to change the way systems operate, and to try to radicalize those involved in order to establish new political forces. Others wish to destroy present forms of government and institutions.

The excesses—if they are excesses—will be redressed, but a return to pre-1960 days is not possible. All of our institutions—whether universities or hospitals—will have to cope with this new view of the organization of our services and of decision making in our various structures. Rather than a development to be feared and fought, it ought to be welcomed by those who have the vision of the gains to be made and adhere to the philosophy which undergirds the basic idea.

The Bases for Citizen Participation

The Ideological Base

The democratic creed—though often violated—serves as the keystone of programs designed to involve citizens in the process by which decisions are reached that affect their lives. This right to participate in the affairs of one's own community cannot be breached. It is given to each individual, regardless of race, religion, or belief. Participation in communal affairs is not limited according to one's station in life. When evidence is presented that such rights are being violated, it is expected that those who espouse the democratic creed will take action to bring about the fulfillment of such rights.

During the past decade, the conscience of the Nation was touched by the evidence of such disenfranchisement among minority groups. In part, the persistent demands of these groups and the willingness which they displayed to use militant tactics, and even violence, served to obtain the legislative and social changes needed to bring the society closer to its own ideals.

But the problem of achieving democratic participation is not limited to minority groups. In a modern era, it is something that must be worked at! Millions of poor persons do not have the tools, knowledge, and skills with which to participate effectively. The high rate of mobility and the even higher rate of density of the urban centers of the country make anonymity the rule, rather than the exception. The "gemeinschaft" of the small hamlet where everyone was known to everyone else—and, therefore, was a significant actor—has been replaced by the impersonal forest of multi-level apartment houses or identical miles of sub-divisions that absorb individuals and families and allow them to go through crises without causing a ripple. The joys, anguish, and

hopes of countless families are muffled by deadening walls that make meaningful interaction among neighbors difficult, if not impossible.

"Give a Damn"—the slogan of the Urban Coalition—is the rallying call for those who are committed to democratic ideals and wish to operationalize the participation of citizens.

Sociological Insights

One ought to be careful not to idealize the past. The rural village and the small town suffered from many defects. However, the service systems in such settings—the bank, post office, hospital, garage, school—were highly personal. The "caretakers" and service agents knew their customers by name and, in turn, the customers were aware of the culture of the various institutions—the peculiar ways of doing business that had developed in each system, often based on the personality and idiosyncrasies of the owner or manager. If a customer wished to deviate from that pattern, he could intervene in the system—appeal—by channels that rarely were threatening to him. In most cases, the route was direct and there were no forms to fill out. His "case" was handled by someone who might have known him from birth, knew the family, and could evaluate the risk without lengthy investigations.

Compare this to the exigencies of our large urban centers and the service delivery systems of the mushrooming public sector: welfare offices, hospitals, large department stores, schools with thousands of pupils, etc. There is impersonality both within the system and in approaching the client. Tasks are divided among many groups of employees. Few have a view of the whole—or concern for the whole. The administrative requirements multiply in order to provide some control for the directors of the system and to maintain a degree of homogeneity in the way decisions are made. The customer is not anymore a neighbor whom we know and wish to please in order to have him return. He is now a number—one of thousands or millions who must be handled in approximately the same way, for fear of inequity or administrative chaos.

Another feature of large organizations—bureaucracies—is that they take on a life of their own. No longer are they seen primar-

ily as vehicles by which service is rendered to persons outside the bureaucracy. Serving the bureaucracy becomes an end in itself. The system, its directors, its budgetary process, its fund-raising ability, its employees tend to become the paramount factors that influence how the service to the customer is provided. Not the customer! This pattern is especially true of public and non-profit organizations which do not depend on the customer for additional gains for the directors or the employees.

The reference groups for the workers in a large governmental organization are not the recipients of the service. They tend to be seen as powerless and often inconsequential. The various professional associations, other members of the service system, the supervisors, etc., are far more important. They grant promotions, status, money. The customer has little to contribute to the self-interest of the employee.

If the customer of services provided by a large institution wishes to prod or to question the basis of some decision affecting his life, he is defined as a trouble maker. Information which he needs to determine the actual policies is withheld from him. He is routed from office to office and made to wait interminable periods of time. Tremendous audacity is needed to question the judgment of the professional or semi-professional in most of these agencies. The fear of retaliation is an ever-present dynamic in such situations. "Don't fight City Hall" is a motto offered as a safer way to survive despite the inequities that may occur.

Consumer involvement as a principle is offered as an antidote to the problems of huge bureaucracies. At a later stage in this paper, we will discuss some methodologies. In essence, there must be some shift in power between the "caretakers" of the system and the users of the system—if that system is to be more responsive to the needs of its customers and to its own mission.

The Lesson of Management and Business

In the area of commerce, the concern with success seems higher than in public and non-profit organizations. A great deal of effort is spent in trying to determine ways of increasing sales and the appeal of the company and its products to the customers. Customer satisfaction in the world of business means higher profits and in today's world, everyone within the company benefits. The

management of America's leading corporations has learned the value of consumer involvement.

The methodologies range far and wide. Market research surveys are used throughout the country. The results are taken seriously and influence directly the decisions made by top-management. "Feedback" from the "target group" is paramount. Consumer advisory boards are used as well as "brainstorming sessions," suggestion boxes, contests, incentive gimmicks, etc. Business has learned that in a competitive world, the company must be responsive to client demands and concerns if it is to maintain its sales records. As a result of this interest and commitment, some of the most important new techniques for the involvement of persons in decision-making have come from the business world or have been developed with financial support from our large corporations.

The lessons from this sector of our community are too important to be ignored in the public sector. Responsiveness is as realistic a goal for social services and rehabilitation agencies as it is for department stores and supermarkets. A quick look at the annual budgets of these public agencies will demonstrate that they are big business, too.

The Therapeutic Impact of Involvement

A key factor influencing the development of consumer participation in many service systems is the massive evidence that there is a relationship between involvement and the achievement of therapeutic goals. The principal contention is that shared responibility for decision-making and for the actual treatment enhances the potential movement by the client. Milieu therapy, ward advisory boards, governing bodies made up of patients are all techniques based on this major idea.

Since this concept is of critical importance to the rehabilitation field, it needs further elaboration. The impact of certain rehabilitation efforts that have negated the concept of involvement has already been documented. The loss of self-determination which often accompanies entry into one of our institutions can offset all the physical therapy and other efforts at helping the individual. It is overwhelming and destructive of the personality. Erving Goffman, in his classic volume, *Asylums*, published nearly ten

years ago, expressed forcefully the impact of our modern, total institutions:

> . . . total institutions disrupt or defile precisely those actions that in civil society have the role of attesting to the actor and those in his presence that he has some command over his world—that he is a person with 'adult' self-determination, autonomy, and freedom of action. A failure to retain this kind of adult executive competency, or at least the symbols of it, can produce in the inmate the terror of feeling radically demoted in the age-grading system.[1]

Writing of the problems of disability from the perspective of role theory, Edwin Thomas, Professor of Social Work at the University of Michigan, outlines the behavioral repertoires that get labelled as disability-related roles.[2] Thomas points to the danger of role asynchrony and invalid role synchrony. Often, there is a generalization from one "true handicap" to other aspects of behavior that are not handicapped. Behavior which exaggerates the actual degree of handicap—on the part of the disabled person and others—is a form of invalid role synchrony which Thomas describes as "the fictitious handicap."[3] Yet, this is the pattern followed by most institutions in dealing with the admission of disabled persons, even if the purpose of admission to the hospital or clinic is diagnosis, rather than treatment. The "consumer" is expected to take on the "sick" role. The role is defined at least in part on the basis of the needs of the system, rather than the disabled person:

> The first general expectation is that of *dependence,* of compliance by the patient to hospital rules and regulations, to the daily routine, to the decisions that are made for him by physicians or nurses. The compliant patient is therefore likely to be perceived as the good patient by hospital staff, whereas the patient who tries to exert authority will be perceived negatively . . .
>
> In line with dependence, the patient is expected not to fulfill his normal role responsibilities . . .
>
> A third expectation concerns the de-emphasis on external power and prestige which the patient carries in his life outside the hospital. The taking away of the patient's clothes is a symbol of this loss, all patients being rendered as naked as the day they came into the world, and supposedly as innocent . . .[4]

While such procedures may help to "manage" the patient or client, and therefore serve the interests of the staff, it is counter-indicated as a treatment mode, is destructive of personality, and violates fundamental rights of all citizens.

The consumer of rehabilitation services cannot take on the dependent role of the "sick" person. Participation in and influence on the rehabilitation service system can change the role behavior of the disabled person and emphasize behaviors that represent strength and normalcy in him. The disabled individual—whether his handicap is economic, educational, cultural, or physical—must not be reduced to impotency. His perception of his own self should include an awareness of his own strength and power. This can be one of the most significant contributions of programs designed to magnify consumer participation.

A new approach cannot be achieved by minor modification. What is required is a fundamental and drastic revision of our way of doing things. The process will be painful and difficult. As Edgar and Jean Cahn state: "Citizen participation is a nuisance. It is costly, it is time consuming, it is frustrating, but we cannot dispense with it. . . ."[5]

The issue is not whether change should occur; it is rather the extent to which consumers can participate and what formal and informal mechanisms can be devised. This will be discussed in the next section.

Citizen Participation Models

The translation of a principle into a workable program can be an arduous task. There are few such tasks as complicated and difficult as the operationalizing of a commitment to the involvement of citizens in a particular field or institution. Hans B.C. Spiegel and Stephen D. Mittenthal were most accurate when they wrote that citizen participation, a seemingly facile subject at first glances, becomes, upon further analysis, a phenomenon of infinite complexity and subtle dimension.

> Truly the more one explores the endless ramifications of citizen participation, the more one appreciates the old adage of 'having a tiger by the tail.' Every effort to reduce its protean-like substance to a definable systematic and comprehensible body of thought is resisted by inherent dilemmas—contradictions between myth and reality, and even between different sets of observable social phenomena. Citizen participation virtually defies generalization and delights in reducing abstractions to dust.[6]

Varied Structures

The structures for citizen or consumer involvement can differ according to function, relative power, auspices, and funding. There are literally hundreds of issues involved in the selection of leaders, the granting of sanction, and the definition of role for such groups. The gradations are countless. At one end of the continuum, it is possible to plan for the involvement of consumers by developing mechanisms for "feedback" through opinion surveys, suggestion boxes, and occasional meetings with sample groups of consumers.

The involvement of citizens can be somewhat deepened by the creation of advisory boards, although these have no actual power

except in the effectiveness of their recommendations as evaluated by those who *do* have power. A further step along this continuum is to grant a few voting places on a board of directors to representatives of the consumer group. In some instances, these representatives are selected by the authorities of the service system because of their knowledge, experience—or their passive acquiescence.

Some critics of such selections view this as "tokenism" and claim that those who are selected are chosen because they can be easily controlled. In some other instances, the representatives are elected either by the total group they seek to represent or by some group that claims to be representative of the total consumer population.

The next step on the continuum is one which gives to the consumer group a majority vote on the policy board. This is the demand that has been heard with more frequent insistence from poverty populations in recent months. The final step on this oversimplified listing of alternatives for citizen participation is one which gives complete control of a program to the consumers—without representation of the usual group of professionals and experts. It becomes a program run and directed by consumers who then set policy and hire and fire staff members. There are numerous examples of all these gradations in our country today.

Varied Purposes

One can also dissect various kinds of citizen participation plans according to purpose. Some groups of consumers are created by a service system simply as a communication system. It is a way of trying to give information to the client population and, in turn, to obtain data from them. Other groups are created to give advice and to help ascertain the areas of priority to be handled by the service system. Citizen groups have been formed to participate in planning and to approve programs to be established. Finally, there are citizen groups to whom has been entrusted the responsibility for carrying out particular programs.

Similar alternatives can be drawn around the issue of participation. Who should be involved? Is it possible to have all consumers involved? If not, should the most capable persons be invited to participate? Whose decision would be binding? Or should

those who are interested be invited to work—as if they were representative of the total group?

The traditional way of involving citizen representatives used by most voluntary associations has been to select those deemed most influential in the community. Should a similar path be followed in ascertaining who should represent a community of poor persons or disabled clients?

During the early days of the War on Poverty, a number of poor people elections were held. It was discovered that few of the poor were willing to participate. Many did not want to be identified as being poor. Others were apathetic. A large number did not understand what purpose was being served by the election. In a few communities, petty politicians took over and obtained support by bribes and promises. Is the problem unique to the election process among poor people? We do not think so. Even an election process —the epitomy of the democratic system—does not guarantee the ideal of citizen participation.

Clarification of Goals

Perhaps the most essential question is one which must be addressed to those who invite citizen participation: Is the goal to obtain support and to neutralize opposition? Or is the service system willing to have citizens make an input into the decision-making process which may go directly against the best judgment of those who direct it? Much of the present efforts to involve consumers is designed to convince the consumers that the programs worked out for them are really just what they need. They are not based on a willingness to share power, or even to listen carefully.

One Urban Renewal official had the courage to speak with candor. He said:

> Organization for participation means mobilizing the community to veto renewal plans. It is self-defeating for government to do this. You can't take a plebiscite about every official action or proposal and a plebiscite is what citizen participation is.[7]

Serious citizen participation efforts require a commitment by the service system to relinquishing some degree of power. There must be an a priori assumption that the end result of the process

will be different than the tentative ideas that were formulated before the involvement of the citizens. Unless such a commitment exists, citizen participation is a sham—an attempt at manipulation or co-optation.

The democratic process, including citizen involvement, does not assure wisdom. The end result may indeed be inferior to the professional's carefully studied proposal. The gains to be made cannot be measured in short terms. At stake is nothing less than the type of society we wish to develop.

How About the Rehabilitation Field?

The issues described above apply with equal force to the various service systems that have as their focus the rehabilitation of the disabled and the disadvantaged. We broadly define the handicapped to include not only those with physical or mental disabilities, but those who have handicaps resulting from age, economic, educational, or social causes. Citizen or consumer involvement cannot be limited to one category. Nor should we exclude institutions where handicapped people reside. Hospitals, old-age nursing homes, special schools and prisons are all rehabilitation agencies. If they do not fulfill such roles, then it is time for them to begin to assume these responsibilities.

We submit that part of the rehabilitative process—as crucial as any other part of the treatment methodology—is consumer involvement. The settings may require differing approaches. Robert A. Scott in *Time* magazine writes:

> The overwhelming majority of people who are classified as blind can, in fact, see and function as sighted persons in most important areas of everyday life. There is nothing inherent in the condition that requires a blind person to be docile, dependent, or helpless. Blindness is a social role that people must learn to play. Blind men are made.[8]

Can a similar accusation be launched at our efforts to help welfare mothers?—the aged?—the educationally deprived?

Edgar and Jean Cahn state the case for citizen participation with forcefulness and clarity:

> . . . participation, in and of itself, constitutes affirmative activity—an exercise of the very initiative, the crea-

> tivity, the self-reliance, the faith that specific programs . . . seek to instill. Participation is, in fact, the necessary concomitant of our faith in the dignity and worth of the individual.[9]

With effective citizen participation come a series of secondary gains to the individual persons involved and to the service system. For the individual, participation often means a new camaradarie and friendships to replace those lost as a result of the handicap or those that were never there. In addition, there is the subtle but important message that he is not alone in his struggle to overcome his fate. The shame and disgrace often felt by the disadvantaged individual is slowly replaced by a new and stronger identity that enables him to speak with candor and force to those whom he previously feared. For the service system, citizen participation provides an opportunity for new insights to guide interventions and treatment strategies. And, if the consumer involvement plan is conceived with sufficient creativity and imagination, it may provide the system with a new cadre of workers to join the professionals in trying to cope with the causes and effects of the handicapping condition.

In our discussion of consumer involvement, we need to distinguish between two major forms. The first is the organization of consumer groups—often independent and not directly related to any service system. A typical example is a welfare rights organization. The other is the involvement of consumers *within* the service system and modifications designed to make the system more responsive to the needs—and the rights—of citizens.

In some of the literature dealing with citizen participation, the consumer groups organized independently are seen as divergent, conflicting, or oppositional, while the citizens working within the service systems are described as having convergent, cooperative, and integrative influences on the operations. Although this may happen in a number of instances, such generalizations are misleading. Independent consumer groups can—and have—worked very successfully in an integrative and cooperative way with the service systems. This has been especially true of legislative efforts. On the other hand, it is to be hoped that citizens participating within service systems will feel the freedom and develop the confidence to engage in serious conflict with the other participants in the system. Conflict is usully the prelude to consensus.

Organizing Consumer Groups For Community Action

> **The Committee for the Rights of the Disabled grew out of the movement that is now gathering steam all over the country—the movement of the poor, (tired of being second-class citizens), to get together, organize themselves and let their voices be heard in matters directly concerning their own welfare. (*Leaflet distributed in Los Angeles, California*)**

Some public officials, concerned with the high degree of anomie among the disadvantaged and the disabled, have recognized for some time the value of citizen participation. Those who have been willing to pioneer with new structures for citizen participation have tended to think in terms of advisory groups, block clubs, area councils, and a number of other in-house activities. We refer to these as in-house because they are sponsored and often financed by the service system, are tied to the decision-making procedures of the system, and, in effect, are controlled by the authorities of the system—even if in subtle ways. These methodologies have a legitimacy of their own. But they are limited in their effectiveness, and especially in winning the allegiance of the target population.

One of the most significant pioneering efforts to organize poor people was sponsored by the Baltimore Urban Renewal and Housing Agency, in an area known as Harlem Park. For a number of years following a decision to rehabilitate that community and involve the residents, community organizers worked diligently with block clubs—offering them the opportunity to design their own inner-city block parks and playgrounds and to advise the officials of BURHA on what ought to take place in Harlem Park.

Despite some limited success, the total effort was not effective. The block clubs had little power, although many of their suggestions were taken seriously. Although attractive to those who

owned their property in Harlem Park, the block clubs did not have the same drawing power among tenants. The most fundamental problem, however, was that the block clubs—the action systems—did not *belong* to the people. They were part of the BURHA machinery. The community organizers did not have clear sanctions to allow—and support—the decisions of their block clubs. Downtown headquarters had something to say about what the workers should do—and what the block clubs should do. Some conflict could be tolerated—provided the club understood that it had to use the *internal* machinery of the bureaucracy to deal with its problems. Several layers of "citizen groups" were established to maintain order and discipline among the block clubs. All clubs were part of an area council which either approved or disapproved the club's action. In turn, all area councils would report to a city-wide body. The administrative chart was beautiful and logical. The agency did not succeed in convincing the people that the structure belonged to them. They *felt* manipulated. And this is the vexing problem with such efforts at community organization of the poor—under official auspices. It somehow does not feel as if it is "their thing."

Advantage of Independent Groups

Independent consumer groups—welfare rights organizations, tenant groups, councils of disabled persons, etc.—may lack resources, expert leadership, and technical assistance. But they have a number of crucial assets that must be emphasized.

First and foremost, there is no question of ownership. The group is organized and led by members of the group and it is "their thing." They make the decisions, without having to clear with the "establishment" or other layers of a citizen participation bureaucracy.

Secondly, the repertoire of strategies is much greater. The group can select militant tactics or resort to press releases. It is also free to select the level of intervention. A tenants' association, for example, can sit-in at City Hall in front of the Mayor's office and skip past negotiations with the manager of the public housing project, the director of the city's public housing authority, and other administrative levels. We are not suggesting that this is the best strategy in all cases, but the *freedom* to choose where

to intervene and whether to escalate a conflict is there.

Thirdly, the consumer group is frankly partisan and speaks for its self-interest. It can negotiate on its own behalf, based on *its* perception of what is wrong with the system and what needs to be modified. For too long, the disabled and disadvantaged had to depend on well-meaning affluent or non-disabled spokesmen to argue their case. Despite the sincerity of such individuals and organizational spokesmen, most had little real contact with the people for whom they were speaking and none was, in any meaningful way, responsible and accountable to them. As Richard Cloward and Richard M. Elman indicate, there have been many civic-minded groups and individuals who have argued for a better welfare system in New York City, but until November 1965, no delegation of public dependents had been received in the office of a Commissioner of Welfare for more than 30 years. "Three decades had gone by since welfare recipients had presented their needs and their grievances directly to the man in charge." [10]

Another major asset is the group's ability to break through the shell of apathy and inaction which so often surrounds the handicapped. The independent consumer group can focus on an immediate issue, often of material importance to its members. It has been suggested that the disadvantaged are not able to focus on long-range solutions. Their struggle for survival requires all the strength they have and life—if it is to be lived at all—must be for today. This perception is quite different from that of the directors of service systems who, necessarily, must take a long-range view of their tasks.

At any one point in time, most public and voluntary agencies are operating on the basis of financial decisions and line-by-line allocations that were initially prepared a year-and-a-half to two years before. It is easy for us to understand, therefore, why bureaucracies, when faced with a demand for change, will so often react with a plan to be initiated in "the next budget" or "the next fiscal year."

Lack of Objectivity

Objectivity is rarely the trademark of an effective social change effort. As Charles Grosser points out:

> Community development in slum neighborhoods is, after all, essentially a process for the redress of grievances that are the cumulative result of the differential distribution of community resources. . . . To avoid partisanship in the name of objectivity and service to the 'total community' is, in effect, to take a position justifying the pittance that has been allotted from the health, educational, and social welfare coffers to the residents of the inner-city slum.[11]

Independent consumer groups do not have to concern themselves with objectivity. They are not responsible for the procedures that may be required within the service system to meet their demands. They are not paralyzed by the conflicting demands of worthwhile activities and competing needs. They are concerned with their lives—and their rights.

In a sense, independent consumer groups are designed to provide the poor and the disabled with communication structures to influence governmental decision-making that are equivalent to those that the rest of society has developed. As the Los Angeles Committee for the Rights of the Disabled indicates in its leaflet:

> Every segment of society, it seems, has its lobbying block. The legislature is constantly complaining that it can do nothing without having some powerful, special interest group mount a high-pressured campaign against it. Other groups have their lobbyists. *But who speaks for the poor and the disabled?* [12]

The perception expressed in the leaflet can be validated by anyone who has been involved in the legislative arena at the national or State level. Lobbying is a part of our governmental process. It permits interest groups to indicate their convictions about their needs and aspirations. The medical and other professions, our major corporations, the lawyers, and the hunting enthusiasts take full advantage of this privilege. So do labor and trade associations and thousands of other groups. It is the American way—and the disadvantaged and disabled must have their opportunity to use it.

In fact, some groups within the population we have classified as disadvantaged or disabled have had a great deal of experience in lobbying. Some of the older groups continue to be influential to this day. Others have disappeared as a result of mergers, new priorities, or changes in the political scene. A significant attempt

to organize the aged took place at the beginning of the New Deal. In 1935–1936, five million old people joined Townsend Clubs organized by Francis E. Townsend for the purpose of promoting a specific program to give $200 per month to everyone over the age of 60. Although President Roosevelt referred to them as the "lunatic fringe," there was real concern in 1936 that the leaders of this group might command sufficient votes to control the election.[18]

Political Power

This instance illustrates another potential asset of consumer groups organized independently. They can, through national organizations and coalitions, wield a great deal of political leverage. This is part of the strategy of the most recent national organization of the poor—the National Welfare Rights Organization. Beginning in June 1966, with forty men and women on relief in Cleveland, the organization has spread throughout the country and has increased its membership to several thousands, with even larger numbers who are willing to join in specific efforts.

The strength of an organization is measured not only in numbers, but also in the potential power it can wield. That power may not be money, but the ability to disrupt or to create a crisis which the larger society cannot tolerate. For instance, it is possible for a public housing manager to evict a family—or even a few families —for non-payment of rent. But a rent strike in which literally thousands of poor families would have to be evicted could not be tolerated by the community. This is precisely what the organizers of militant tenants' associations wish. Their power is derived from the loyalty they command and the potential threat of mass confrontation.

Such militant methodologies are questioned by the directors of service systems, as well as by the general public. The advocates of militancy for the poor and disabled argue that these are the only alternatives open to this population and that the affluent, the middle class, and other groups in the society have more subtle, but equally effective, methodologies based on the sharing of values between middle-class bureaucrats and middle-class citizens, the use of money with which to purchase advocacy services, and a greater knowledge of, and relationship with, the political system.

How To Organize

The variables that affect the success of consumer groups include the following:

1. The degree to which a specific issue has been identified.
2. The auspices for the organizational effort.
3. The quality and skill of the leaders.
4. The degree to which the nature of power is understood.
5. The feasibility of the action plan. Can some success be achieved in the relatively near future?
6. The correct mix between a task focus and group maintenance activities.

Each of these variables will be discussed briefly:

Specific Issues

Reference has already been made to the need for specificity in trying to arouse poor or disabled people from their apathy or pre-occupation with their immediate individual problems. The goals of the group ought not to be diffused and abstract. There ought to be some catalytic, immediate issue that is *felt* by those who are expected to belong to the organization. For some years now, attempts have been made to organize persons on the basis of shared geographic location: the block club is a prime example of this. Once enlisted, it was presumed that the member would remain active and participate in a whole range of issues over the years. In more recent years, an alternative model has been suggested for neighborhood organization. It is based on the observation that membership in any action system—even a block club—is not static. It ebbs and flows, depending on the degree of crisis and the interests of the members. No group can operate permanently at a level of crisis. Nor should we assume that everyone in

a neighborhood shares the same concern for all issues. Even in a slum area, there are old-timers and new-timers, owners and renters, young and old, persons on welfare and persons employed, the disabled and able-bodied. Organization around specific issues of those who are affected by such issues seems more appropriate. Welfare mothers form a group based on a very specific common fate and set of concerns. Tenants in a public housing project can be organized on the same basis. In a middle-class community, one can also use a similar strategy—in organizing, for instance, parents of retarded children. This does not preclude the development of coalitions at a later stage—even symbiotic coalitions, in which there is no common goal, but a willingness to support each other's individual goal to maximize political power.

The Auspices for Organizational Effort

Despite the sincere wishes of many professionals and civic leaders to be of help and to find effective ways to relate to the consumer organization, it is essential that the group develop full autonomy. A group of welfare clients organized by a department of public welfare is suspect from the very onset. Reacting suspiciously to attempts by welfare departments to organize their own forms of citizen participation, Richard Cloward and Frances Piven assert:

> To be listened to by the powerful conveys a sense that one is at last wielding a measure of influence, that progress is being made, that genuine reforms will follow. All this is illusory, but until an autonomous movement can gather the strength to compel genuine reforms, the illusion will be difficult to dispel.[14]

The consumers must eventually have full control of their organization. The group has to achieve independence and even the neutral organizers—social workers, settlement houses, or church groups—must be prepared to play a fast decreasing role. This does not mean that such groups cannot be helped by others. That help, however, must be given without an expectation of quid pro quo—or even the anticipation of gratitude. Few of the genuine consumer groups have been able to be organized and led by persons who are not indigenous to them.

A notable exception is the National Welfare Rights Organization, which is led at the present time by Dr. George Wiley, a physical scientist who, to the best of our knowledge, was never on welfare nor needed to be. But Dr. Wiley has had to forego his own professional activities and throw his lot in with his constituents in order to maintain his position of leadership. In a real sense, in consumer organization, "the blind must lead the blind."

Technical assistance can be provided by interested agencies and by the Federal or State government through grants, contracts, and other forms of support, provided that policy determination and control is left to the consumer group. Increasing attention is being given to the use of a consumer group as a service system, offering special programs sponsored directly by the independent consumer group. This will be discussed in another section.

The Quality and Skill of Leaders

Leadership is a precious ingredient in the successful organization of citizens. It is a factor that is rarely controllable. It cannot be imported, nor can it be developed through a crash program in techniques of discussion, leadership, and parliamentary procedures. One of the revelations of the efforts at citizen participation fostered by the War on Poverty is the extent to which there are among the disadvantaged and disabled individuals who can rise to the occasion and take on the mantle of dynamic leadership.

A by-product of the social revolution which combines the civil rights and poverty efforts is the emergence of a rather significant cadre of effective leaders among the poor and the minority groups. The style which they may choose will, indeed, differ from that of the affluent groups in the community. Theirs is a style that is singularly appropriate to their followers and to the challenges they face.

The education of these leaders does not follow conventional routes. Courses in colleges and universities may not be helpful. Inter-city conferences, workshops sponsored by the national federations of such groups, and a great deal of "on-the-job training" provide a more relevant mechanism for the development of their skills.

Just as any political leader in an Irish, Italian, or Jewish area must maintain a style that indicates that he is still "at home" among his followers, so must a leader of a consumer group. He must resist the temptation to become more like the officials with whom he has to deal, or to begin to live according to their style. This temptation is not imagined. It is real and unusually strong and has been the downfall of many who began to emerge as leaders of citizen groups. The directors of service systems must understand this dynamic and the need of the leaders of consumer groups to remain identified not only in views, but in style as well, with their constituents.

Understanding the Nature of Power

People band together in groups for the purpose of trying to accomplish certain ends. The very act of organizing is based on a conscious or unconscious realization that change occurs in society through the exercise of power. The democratic system—with its political parties—is based on the assumption that every citizen has a specific amount of power with which he is endowed and that he will join others in the use of this power. Somehow, the word power has become suspect and has acquired a sinister overtone. In part, this is due to the use of the term by persons who have invested it with specific ideological or revolutionary implications.

An accurate use of the terms "black power" or "poor power" ought not to bring on undue fears and reactions. If black people band together to affect their conditions, they are acting in the best traditions of a democratic system. Most issues in a democracy are not resolved through an intellectual process—nor through a mystical approach. They are resolved by the actions and reactions of power systems—that occasionally coalesce, struggle with each other, or compromise. Saul Alinsky, one of the pioneers in grass roots organizations, states bluntly:

> The power concept must be seen nakedly, without the sordid raiment which serve more as disguises for our own inability or unwillingness or timidity to get involved in a controversy in which we may get smeared or hurt.[15]

Consumer groups have as their primary purpose the develop-

ment of power—acquired through larger membership and through their use of various methodologies that render them more effective (powerful). One of the lessons taught by Saul Alinsky is that such groups do not require the active participation of every person affected by a problem.

In the actual governmental processes, power is increased or reduced according to a whole range of factors. Unlike the ballot box, which grants to each citizen an equal share of power, government—and, indeed, service systems—react differentially to various individuals and groups. The Governor of the State of New York has considerably more influence than an aged widow in Jackson Heights. Service systems react to requests on the basis of an instantaneous diagnosis of the power of the individual or group. The sanitation department's reaction to a request to make an extra garbage pick-up in a fashionable residential area may be quite different from its reaction to a similar request from the inner-city neighborhood.

Since consumer groups of disadvantaged or disabled citizens do not have the normal prestige and power of their more affluent counterparts, they need to search for other procedures that will increase or multiply their effectiveness.

The Feasibility of the Action Plan

Although we have referred to this in an earlier section, stress must be placed on the concept of some immediate gratification. It is only through the achievement of some initial success that a group can develop momentum and increase the support it has from the so-called "target population." This is one of the tenets of Alinsky's plan for successful organization: "The program should be 'specific, immediate, and feasible' in order to create self-respect through success." [16]

This is especially important for the populations we have been discussing. Tragically, many disadvantaged and disabled persons have been "organized" before, only to find that the groups that had promised them some modicum of change in their lives had failed. For those who have never participated before, there are bound to be misgivings and perhaps even a degree of fatalism. The initial success—though a minor achievement—can serve to reinforce identification with the group and its purpose and begin to develop a stronger sense of confidence that "things can change."

The Correct Mix Between a Task Focus and Group Maintenance Activities

A consumer or citizen group exists primarily to address itself to unresolved issues and needs as expressed by the members. It therefore must have a strong task focus. There is a job to be done and this is why the organization has been created. In a good organization, the leaders are also aware of the fact that, to maintain solidarity and participation, attention must be paid to other needs of the members. A group—if it is to maintain high morale —must also provide a pleasant, supportive, and reinforcing experience for the members. The labor unions learned this lesson many years ago—as have churches and other voluntary associations. The bingo game in a union hall or a church meets a very concrete need of some members—as human beings. The disadvantaged and disabled are often highly anomic persons. They have few meaningful relationships with their neighbors, and even fewer persons on whom they can count for friendship. For them,

belonging to a welfare action group can mean far more than the opportunity to influence legislation or obtain certain rights. It can become a setting in which friendships are formed and a new way of life is found. This, in turn, reinforces the commitment of the total group and provides a stable, dedicated membership.

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In this section of the monograph, we have discussed some aspects of successful citizen or consumer group organization. We have insisted that basically such groups must have independence and autonomy. Often, they may come into conflict with the service systems which affect them. Although such encounters may be harassing and painful, we believe that such encounters are essential to the development of a responsive and effective service system and the realization of its mission.

In the next section, we will examine methodologies that can increase consumer involvement *within* the service systems, recognizing that these two approaches are not mutually exclusive. There is a need for independent consumer groups and there is a similar need for changes within the structure of our public and voluntary institutions in order to maximize consumer input.

Engaging The System

". . . I am sorry. We do not give information on the telephone."

"The form must be filled out in triplicate, and notarized . . ."

"The policy of our agency requires that the person in need present himself at our downtown office."

"We close at 4:30 p.m. Come back next Monday . . ."

These are typical bureaucratic responses to a call for help. The size of our service systems and the layers of structure create formidable obstacles to those for whom these various agencies have been created. The persistent complaint is that the process of getting service is interminable, highly impersonal, and inflexible. "It's as if they really don't care," said one clinic patient. A maid, she had spent the entire day in a reception room waiting for a regular diabetic test that takes only a few minutes. In the process, she had lost a day's wages.

One of the major reasons for involving consumers within our service systems is for them to influence the way our programs of rehabilitation are organized. Their insights can guide us in evaluating and increasing the effectiveness of our methods. But the problem goes deeper. The dichotomy between service systems and their client groups has grown too large. Instead of a partnership involving all segments of the community, the programs tend to be seen as the patronizing acts of those "who have it made" for those "who don't count."

The four objectives which the Model Cities administration has identified for its program of citizen participation summarize the basis for a major revamping of our rehabilitation service systems

to maximize the involvement of consumers within both the policy and service structures:

- acknowledging the basic social right of people affected by public programs to have access to and influence on the process by which decisions about their lives are made;
- accepting the fact that even the best intentioned officials and technicians are often, by their training, experience, and life styles, unfamiliar with, or even insensitive to, the problems and aspirations of the Model Neighborhood residents; therefore residents' ideas and priorities will result in a more relevant, sensitive, and effective plan;
- recognizing that the process of participation makes it possible for those citizens formerly excluded from the system to learn how it functions and how to make it function in their interest—that the process makes it possible for residents to strengthen existing skills and to develop new skills, the kind of skills needed to maintain a dynamic neighborhood long after the Model Cities program has ended;
- meeting the reality that generations of exploitation, or what has been perceived as exploitation, has created considerable distrust of public officials among poor people by guaranteeing neighborhood residents technical assistance in planning which is trusted by them.[17]

In the rehabilitation field, service systems vary greatly as to size, sponsorship, function, and structure. No plan developed for one particular institution is automatically applicable to all. There are no panaceas and few well-tested principles. We still face the dilemmas and knotty issues that emerged a few years ago when some blue-ribbon advisory and policy-making boards were transformed by the first appearance of consumer representatives.

Before reviewing some of the major areas in which key advances can be made to involve consumers and improve the responsiveness of our agencies, three crucial points must be made:

First, citizen participation is not a substitute for basic improvements in the quality of the services given. There exists a gap between our knowledge of therapeutic procedures in dealing with both the disadvantaged and the disabled and our ability to prov-

ide such services. Many of our programs are starved for funds and, often, the lack of response is not due to indifference or bureaucratic isolation. It is due to the lack of sufficient money. The involvement of consumers will not solve that issue directly.

Secondly, the need to decentralize our service agencies is beyond question. The problems of a huge bureaucracy can be reduced if the mammoth buildings are abandoned and replaced by neighborhood or district service centers—with delegated authority and local involvement of citizens. No fire department or police department would commit the folly of centralizing all its staff and equipment in one building in a major metropolitan area—even though it might be economical and efficient in terms of equipment utilization, staff meetings, central records, etc. To fight fire or crime, the resources of these agencies must be dispersed and placed close to the potential crisis. The same logic applies to fighting social crises. There is no way by which a service system can be truly responsive to consumers if it is housed in a monumental structure far removed from the localities it is serving.

Thirdly, there is a good deal of evidence that many staff members are insensitive to and unfamiliar with the views and feelings of their clients. This condition ought not to be accepted as permanent. There is much that can be done to train and sensitize the present staff and board members of our various rehabilitation service systems. The gap that separates our staffs and clients can be reduced through imaginative and effective training.

We have emphasized these three observations, not to lessen the importance of consumer involvement within our service systems, but to indicate equally significant steps that need to be reviewed concurrently. Citizen participation—crucial as it is—is no cure-all.

There are four major areas of function which we will review in order to indicate some ways by which the consumers of service can be involved:

1. Planning and policy determination.
2. Provision of service as employees of the service system.
3. Funding of specific programs to be directed and staffed by consumers.
4. Establishing an advocacy program within the service system.

Planning and Policy Determination

Under the impetus of the "maximum feasible participation" concept enunciated by the legislation for the Office of Economic Opportunity, a large number of institutions and other types of service systems began to appraise critically their planning and policy boards. Many thought that they had dealt with the problem of consumer representation by establishing advisory boards, either composed entirely of consumers or including a significant number. Ten years ago, this might have been perceived as a constructive step.

Today, the creation of advisory bodies is seen as a delaying tactic by those who are insisting on consumer representation as a matter of right. Advisory boards—by definition—have no power. The decision-making is left to another body of either lay or professional personnel. This is not "a piece of the action." It is, at best, a belated recognition of the exclusion of those most affected by the activities of the service system. This may seem a harsh dismissal of a progressive idea. The fact is that the disadvantaged and the disabled must be granted some degree of power within the service system. Without the right to exercise a vote on all the matters that normally are brought to a board of directors, the handicapped population served by the institution will still feel excluded and impotent.

The experience of agencies and institutions that have granted voting power to representatives of the clientele being served has, thus far, demonstrated that their presence has not destroyed the institution, nor has it limited the effectiveness of the services given. On the contrary, in many instances, the staff members and consultants have described the mutual respect and understanding that developed as a result of increasing candor and confidence on the part of the total group.

The process involves destroying myths that plague not only the staff, but the client group as well. The communication problem—though not solved by any means—is lessened as the consumers' grapevine system is used to correct distortions and pass on accurate information. Distrust is reduced. Representatives of the clients become aware of the complexity of issues, and often for the first time, realize that some solutions bring with them newer and perhaps equally difficult problems.

The dilemmas involved in the selection or election of representatives of the consumers have been discussed earlier. Community Action Agencies and the newer Model Cities boards have attempted to cope with at least two problems that the disadvantaged face when selected to serve on policy and planning bodies.

The first is the question of reimbursement for the expenses involved in attending meetings. This has ranged from the payment of transportation costs to baby sitting services and dinners, and, in some instances, the provision of stipends. Initially, the payment of such fees may seem to violate the concept of voluntarism which serves as the basis for the participation of most board members. It may also suggest a further co-optation of the representatives, who may be seen as benefitting materially from their participation.

Yet, with persons whose incomes are extremely limited, the cost of involvement is a serious obstacle to "engaging the system." It seems to us that, at the very least, the actual expense of attending meetings ought to be reimbursed by the service system. This should cover all such costs, including the provision of care for children at home. The payment of a stipend may increase the competition for the posts involved and result in the possibility of better representation. In Denver, Colorado, the Model Cities program is experimenting with the payment of $15 per meeting, to cover honoraria and expenses. Officials in Denver report the astonishing fact that seventy percent of the planning committee members are male.

The second problem is that of technical assistance. Planning and policy determination require the amassing of a wealth of knowledge, the careful assessment of facts, and analysis of options. If the consumer representatives are to play a significant role, they must be able to fathom the meaning of agenda items and the various proposals submitted by the staff or others. It may not be enough for the executive director to patiently explain the issues.

To be effective, the consumer representatives may need to have available to them independent technical advisors whom they trust and who will assist them in examining the issues at stake and the alternative avenues for coping with them. Arrangements can be made by the service system to employ such personnel as consultants—or the representatives may be offered the opportunity to

select their own consultants on the basis of standards established. This may appear cumbersome and complicated to the person for whom even the concept of voting consumer representatives is somewhat strange. Without such help, however, the representatives may be forced to be passive observers or "rubber stamps."

There are other techniques for giving a significant role to clients within a service system. For example, a consumer board may be established which must regularly review all policy decisions for the institution or agency. In some instances where such groups exist, they have been given veto power in certain policy areas. We can expect to have many additional models of citizen involvement in planning and policy boards from experiments now being conducted by the two new major social programs established in the past five years: the Community Action agencies and the Model Cities programs:

Employment in the Service System

The literature dealing with the employment of poor persons within social service organizations has mushroomed during the past few years. The concept of "new careers" is generally known and there have been numerous pioneer efforts to redefine tasks in such a way that various levels of activities are identified for persons who lack professional training.

The development of employment opportunities for consumers of rehabilitation programs within the various service systems is but a part of a much larger societal issue. To a large extent, America's pattern of open upward movement has become myth during the past half century. Careful study of the various educational and employment systems reveals that there is an alarming lack of connections or "bridges" from one level to another. The community college graduate may not be able to move on to a bachelor's degree automatically. Education can lead to a dead end. The requirements for professional licenses in certain fields exclude persons with interests and skills who may lack the proper professional credentials, but who would be eligible for professional types of positions in overseas countries or in the military system. To use a now familiar phrase, the opportunity structures are clogged.

Still, we complain about the lack of adequate manpower to op-

erate our institutions. There is a shortage in every one of the helping professions and in many of the ancillary fields.

The message is clear. If we can redefine jobs and identify the skills needed for various levels of tasks to be performed—there ought to be opportunities for our clients to become gainfully employed within our service systems.

But we can go much further. We can create jobs that never existed before and make use of the unique skills and wisdoms of the handicapped persons with whom we work. In some instances, it will require us to recognize new roles that they can perform, precisely because they are members of a disadvantaged or disabled group. They have entry into a community or sub-community which is often denied to "outsiders." One such role is that of "social brokerage"—pioneered by Mobilization for Youth in New York City. This means, according to Harry Specht,

> . . . involving low-income people by recruiting isolated individuals for newly formed primary-type groups in order to make better use of public and private agency resources . . . The technique is called 'social brokerage' because the organizer fulfills the function of broker between the client and the social agencies.[18]

In other instances, handicapped persons can be trained for *traditional* tasks to be performed in *new* settings. Such is the case, for example, with mothers who are being trained to provide day care in their own homes for the children of neighbors who are participating in work training.

By emphasizing the strengths of the handicapped person, a large panorama of possible employment opens up. In a sense, we are faced here with the problem of the self-fulfilling prophecy. If defined as real, a situation becomes real in its consequences. This can be a positive or a negative force.

The Federal Government has met with significant success in providing employment for mentally retarded persons under a special hiring authority established by the Civil Service Commission. In existence since 1963, this program has placed more than five thousand mentally retarded persons in over one hundred different jobs in forty different Federal agencies throughout our Nation.[19] The success of this program, operated with the advice of the Vocational Rehabilitation Administration and the State Vocational Rehabilitation Departments, indicates that jobs can be developed

for the disabled, as well as for the disadvantaged.

The one caution we would add is to relate the employment program to an educational one as well. Whether we like it or not, educational institutions provide individuals with "passports" that permit mobility vertically and horizontally. No "new career" program can be deemed as valid unless it gives each participant an opportunity to climb to another level on the educational ladder. This applies equally to the person in need of a high school degree as it does to the holder of a B.A. degree.

Funding Consumer-Run Programs

The neighborhood corporation represents another important idea for consumer involvement and consumer control. It is a logical extension of the concern we have expressed for self-help and the dignity that comes from autonomy. Rehabilitation systems may be able to adapt the same concept to their work. Are there certain activities which can best be carried out by present or former consumers? Can these activities be isolated from the rest of the program so that they can be performed independently? For example, case finding may be an important task associated with the initial phase of a rehabilitation effort. In another situation, the operation of a communal day care center may represent the first tangible assignment that can be turned over, through a subcontract, to a consumer group already existing or formed for that purpose.

We cannot underestimate the therapeutic value to a disabled or disadvantaged group of being able to operate a program—no matter how limited in scope—with total responsibility for all its aspects. Here again, technical assistance may be needed and there should be some flexibility to permit the group to make its mistakes.

In recent months, it has been suggested that poor persons can be used to provide technical assistance and support as members of consulting teams organized to assist in the development of new programs. They would not substitute for the use of competent professional personnel, but would add to the strength of the consulting or advisory team by sharing their unique perceptions and engaging other poor persons in more open dialogue than would otherwise exist between professionals and poor people.

As with all other aspects, this type of citizen involvement carries with it certain risks. The desire to involve has to be placed in the context of a concern for high standards of service, careful and legitimate use of public funds, and objective evaluation. Contracts need to be drawn with care. The responsibilities of the sub-contracting group must be crystal clear. Where problems have occurred, they have been largely due to confusion and a lack of legal sophistication on the part of the consumer group. Difficult as it may seem, this idea may have great value to the disabled and disadvantaged, as well as to our service systems.

An Advocacy Program Within the System

During the past few years, the appeals lodged by welfare recipients dissatisfied at the decisions made by their workers have risen at a very rapid rate. The reasons for this increase are not difficult to find. A few years ago, most welfare recipients did not know that there was an appeal procedure. Those who did were often unaware of the specifics, feared retaliation, or did not have the skills to collect the sort of evidence they would need. Now, the various organizations that have focused their attention on welfare are eager to inform welfare clients of their rights and to offer consultation and legal advice if needed.

To many workers in the service system, such appeals are annoying. They waste time and create much additional paper work. In addition, an appeal seems to reflect on their competence and their ability to interpret the regulations correctly. Though the workers may agree as to the legitimacy of appeals, there is something about the entire process that many find troublesome.

The reaction of welfare workers to appeals is not at all unique. Similar reactions can be found in any and every system—including the university, the army, hospital, and clinic, etc. In brief, it is found in every human organization. Still, the individual needs protection and that need has never been greater than now. Confronted by a huge bureaucracy, he feels unequal to the task of protecting his rights or stating his case. He is alone—unfamiliar with the ways the system operates and the bases for the determinations of his worker. The worker seems to him to be both his adversary and judge. His perception may be distorted—but from

his perspective, such distortions are understandable.

Faced with similar problems, the United States Army established a specific position—that of the inspector general. The I.G. is not part of the chain of command. He may be seen by anyone who feels he has a legitimate complaint. The I.G. is given unusual sanctions to move in and out of various parts of the army bureaucracy in order to ferret out the truth. In Sweden, the ombudsman serves a similar function to "keep the system honest." Established in 1809, the ombudsman is responsible to the legislature. His function is to investigate citizens' complaints against public agencies. He is a public investigator and grievance commissioner combined, with power to investigate administrative agencies, examine their records, and call witnesses. This system has spread to other Scandinavian countries, to New Zealand, and West Germany. Traditionally in this country, however, the individual or group that wished to challenge a ruling on the part of an institution or agency could do so by following certain prescribed steps—but with little help from the system itself. The challengers would invariably have to turn to some outside agency or private advocate for assistance.

The disabled and disadvantaged are rarely in a position to turn to other systems for help, or to engage the services of a lawyer. If their rights are to be protected and the "system" kept honest, some new devices for this purpose must be created.

The basic premise which has to be established at the onset is that the service system is obligated to establish, give sanction, and tolerate a set of well-defined procedures by which appeals can be made and grievances heard.

The institution or agency staff will need careful training in recognizing the legitimacy of such procedures, assisting the individual or group to follow the necessary steps and withholding verbal or non-verbal disapproval of the use of this process.

Having established the premise, there seem to be two routes that can be followed in creating a program that will provide the consumers with advocacy services.

The first is to provide within each service system an office of advocacy, manned by a member of the staff who has both special responsibility and authority. This individual would be given the power to act within the system to make certain that his client receives the full benefit of the program of the agency. He would

function as a sort of institutional public defender and be available to all who wished to "fight the system." He would have a small staff of present or former consumers to assist him.

The second alternative is to accept and encourage the role taken by some independent consumer groups as the advocates of specific clients in their disputes with the service systems. The National Welfare Rights Organization, for instance, has urged its chapters to assume such a role. In Philadelphia, the welfare rights organization has been granted the private use of an office in each of the branches of the Department of Social Services. In Baltimore, a group of welfare mothers insisted that the Department of Social Services provide a telephone at a desk to be used by the welfare rights representative and advocate, and also give them a copy of the manual of welfare regulations.

The major drawback to the second alternative is the need for financing. Advocacy is an expensive process, especially when dealing with individual grievances. Perhaps such advocacy structures can be funded through a sub-contract to a consumer group or some other non-profit group or corporation. There is also a good deal of merit to the establishment of an ombudsman-type position within the service system. The latter might be granted a great deal more power to investigate and influence decison making than the former, though we would need to overcome the usual distrust of a public official.

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The list is not exhausted. Citizen participation methods and techniques are still at a primitive stage of development. The application of any one idea or suggestion needs to be carefully weighed. There is a whole range of unresolved dilemmas. Among these are the relationship of various categories of disabled and disadvantaged persons with each other; the communication between representatives and their total constituency; the handling of major and clear-cut differences between professional judgment and consumer opinion; disputes among consumer groups and the multiplication and fragmentation of such groups. Caution does not mean to slow down or stand still. Progress will only be made if persons are willing to be bold and experiment on the basis of their commitment.

Statutory Provisions for Consumer Participation

> Involvement and active participation by the poor do not, it must be understood, rule out important roles for the other parts of the community. The very concept of community action means that the *whole* community is involved . . . From the outset, the poverty program has been embroiled in countless endeavors to give life and meaning to the words 'maximum feasible participation.' Such was our mandate, written and enacted by Congress, signed by the President of the United States, hallowed by historical precedent, and now reconfirmed by pragmatic experience. *Sargent Shriver* [20]

A basic policy—if it is to move beyond rhetoric—needs to be translated into specific programs which are then funded. To insure that the program which is to be established fits within the objectives of a policy, specific rules and regulations are drawn to cover the activities of the staff and the decisions to be made during the operation of the program. This is the way a legislative body insures its basic decisions. Sometimes, the statutes are very specific and sometimes they leave a great deal of discretion to the administrators. Always, they try to reflect the intent and the philosophy of the body that enacted the law.

In establishing advisory boards and commissions, the legislature can, by the degree of specificity, reveal its biases and its priorities. An example will illustrate the point. The following is a section of the ordinance establishing the Baltimore Coordinating Commission on Problems of the Aging:

> . . . The Commission shall consist of twenty (20) members, sixteen (16) of whom shall be appointed by the Mayor as hereinafter provided. Of the sixteen (16) members appointed by the Mayor, two shall be members of the City Council of Baltimore, one a representative

> from Baltimore City of the Medical and Chirurgical Faculty of Maryland, one a representative of labor, one a representative of industry, one member shall be specially knowledgeable in research, one member shall be associated with the work of charitable organizations, two members shall be selected because of their interest in problems of the aging, and six members shall be selected because of their general interest in such subjects as housing, religion, charitable matters, and the public good . . . The remaining four members of the Commission, ex officio, shall be the Director of the Baltimore City Department of Welfare, the Baltimore City Superintendent of Schools, the executive head of the Baltimore Urban Renewal and Housing Agency, and the Superintendent of the Baltimore City Bureau of Recreation.[21]

In addition to revealing the sharp contrast between statutes drawn in 1963 and those that are apt to be issued in 1969, this excerpt demonstrates the degree to which statutes can channel newly created structures in one direction or another. The decision to include representatives of certain specific professional organizations is a reflection of the power which such groups hold. The same may be said of labor, industry, or, indeed, the various governmental bodies operating at a city level. The absence of consumer representatives is striking, as is the balance of interests represented on the Commission.

A review of the statutes that govern the composition of national commissions and advisory committees demonstrates that the problem exists in Washington as well. Most of the statutes still call for "blue ribbon" individuals: recognized authorities in professional or technical fields, civic leaders, leaders of programs, etc. Precedents are set, often at the national level. The representatives of the disadvantaged and the disabled need to be built into the language of our statutes and the administrative directives that establish national review panels, advisory committees and task forces.

Another function performed largely at the Federal level which has far-reaching impact is standard setting. As the distributors of funds for rehabilitation activities, the Federal agencies can set standards which must be met before a program is defined as workable and eligible for funding. By holding the carrot—consulting and cajoling—the "Feds," acting on the basis of statutes,

have changed dramatically the nature of service delivery in the entire United States. The desire to share in the allocation of funds is strong and there are few organizations and institutions at the local level that will abandon attempts to conform to the national criteria required for funding. If the statutes are vague and leave wide areas open for interpretation—they will be interpreted on the basis of the philosophy of the *local* community or agency. In many cases, the principle of minimum effort will prevail. On the other hand, clearly stated and firm guidelines will produce astonishing results when accompanied by the anticipation of substantial funding.

Obviously, one cannot generalize about the way statutes should be written. The decision is bound to be influenced by political, administrative, historical, philosophical, and highly pragmatic factors.

Both the Office of Economic Opportunity and the Department of Housing and Urban Development have learned that in the area of citizen participation, standards need to be outlined with precision and detail. The OEO Instruction on the participation of the poor in the planning, conduct, and evaluation of community action programs identifies such detail as the minimum number of meetings to be held, the definition of a quorum, and how minutes shall be kept. The minimum performance standards for citizen participation in Model Cities are broader, but they contain six major—and concrete— points:

1. ***Structure***

   '. . . there must be some form of organizational structure . . . which embodies neighborhood residents in the process of policy and program planning . . .'

2. ***Representation-Representativeness***

   'The leadership of that structure must consist of persons whom neighborhood residents accept as representing their interests.'

3. ***Sufficient Information***

   'That structure must have sufficient information about any matter to be decided . . . so that it can initiate proposals and react knowledgeably to proposals from others.'

4. ***Technical Assistance***

'. . . the structure must have the technical capacity for making knowledgeable decisions . . . some form of professional technical assistance in a manner agreed to by neighborhood residents shall be provided.'

5. ***Financial Assistance***

'Where financial problems are a barrier to effective participation, financial assistance should be extended to neighborhood residents . . .'

6. ***Employment of Residents***

'Neighborhood residents will be employed in planning activities . . .'

The field of citizen participation has changed dramatically from the days when the creation of an advisory panel of distinguished and affluent civic leaders would meet the minimum standards established for citizen participation in urban renewal projects. As we look at today's statutes, we become keenly aware of the distance that we have travelled in just a few years. We are also sobered by the realization of the advances that still must be accomplished in our mission to establish one America, in which all citizens can sense their equality and participate, despite their handicaps.

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Appendix

The Poor in the Community Action Program—A Summary of Rights*—

Poor people in the community action program have a right to:

1. Organize themselves into workable and responsible neighborhood or target area groups to take action on problems and issues of poverty that concern them and to be given help (technical assistance, training, staff assistance and funds where possible) by the community action agency to strengthen their ability to act effectively to erase poverty.
2. Take part in major policy decisions regarding the planning and operation of the community action agency and its delegate agencies through their democratically-selected representatives on the Board.
3. Be fully informed about the policies and operations of all community action agency and delegate agency programs.
4. Expect the community action agency to provide a forum in which they can make their views known to the community on the poverty problems of the community as they see them and can propose solutions to clear up those problems.
5. Attend and take part in all public board and public policy making committee meetings of the community action agency, its delegate agencies, and neighborhood or target area councils.
6. Be assured that the community action agency is providing job and career development opportunities for poor people through the community action agency and its delegate agencies.
7. Suggest needed programs which should be considered for funds from the community action agency, the Office of Economic Opportunity, and other local, State, or Federal sources

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*This is a summary of OEO Instruction 6005–1. The Instruction should be looked to for the complete OEO policy on participation of the poor. Published by the Office of Economic Opportunity, December 1, 1968.

of funds. (Funding proposals should be submitted through the community action agency.)

8. Obtain OEO Instructions, guidance, and program handbooks that have been distributed to the community action agencies and have an opportunity to comment on OEO draft instructions sent to community action agencies for opinions. (These comments should be attached to any response made by the community action agency to the Office of Economic Opportunity.)
9. Expect the community action agency to work for involvement of the poor in the planning and the conduct of other local public and private agencies for organizations serving the poor community.
10. Petition for representation if they feel their organizations are not adequately represented on the community action agency board and be heard in a public hearing to be held by the community action agency after it has received the petition.
11. Express themselves, either as individuals or groups, directly to the Office of Economic Opportunity Regional Offices and Headquarters if they have complaints about the operation of OEO-funded programs.

Representatives of the poor have the right to:

1. Raise to the attention of the community through the forum provided by the community action agency the problems and issues of poverty which must be faced.
2. Participate fully in the activities of the community action agency board.
3. Be fully informed and provided with the necessary tools, including training, technical and staff assistance, to permit them to participate fully in the activities of the community action agency board.
4. Be assured that community action agency board and committee meetings are run under open democratic procedures, that meetings are held at a time and place convenient to the representatives of the poor.

Representatives of the poor have an obligation to:

Represent the views of their constituency (those they were selected to represent) in the meetings of the community action agency and its delegate agencies, report back to their neighborhood or target area fully about the meetings and the progress of the community action agency, and discuss with their constituency the issues which will come before the next board meeting to get their directions and contributions.

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